

# CELEBRATING THE TORCH WITHIN

IRSF 25<sup>TH</sup> ANNUAL EDUCATION  
& AWARENESS CONFERENCE

*PROGRAM SUBJECT TO CHANGE – CHECK MESSAGE BOARDS*

| DAY                    | TIME                                                               | SESSION                                                                                                                      | SPEAKER                                                                                                     | SESSION TYPE/LOCATION         |
|------------------------|--------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------|-------------------------------|
| <b>Friday-Monday</b>   | Fri: noon-9pm<br>Sat: 7:30a-7:30p<br>Sun: 7:30a-6p<br>Mon: 8a-noon | Registration/Help Desk<br><br>Bookstore: Awareness items, educational materials. (Silent Auction tables - Saturday only)     | IRSF Staff and volunteers                                                                                   | Ballroom Foyer And Ballroom C |
| <b>Saturday-Sunday</b> | 9am-5pm                                                            | Exhibitors and Information Booths: Assistive technology, adaptive equipment, Aurora Recording, fundraising, clinics and more | Exhibitors and IRSF staff                                                                                   | Ballroom Foyer                |
| <b>Friday May 22</b>   | Noon-9p                                                            | Registration open                                                                                                            | IRSF Staff                                                                                                  |                               |
|                        | 6pm-10pm                                                           | Dinner                                                                                                                       | At your leisure                                                                                             | Riverside Hearth Restaurant   |
|                        | 7:15pm                                                             | Welcome orientation and IRSF Update                                                                                          | Paige Nues, IRSF                                                                                            | General Session Ballroom A    |
|                        | 8pm                                                                | Crackerbarrels: Hopes and Expectations                                                                                       | Session Facilitators                                                                                        | Concurrent                    |
|                        |                                                                    | 7 yrs and under                                                                                                              |                                                                                                             |                               |
|                        |                                                                    | 8 – 16 yrs                                                                                                                   |                                                                                                             |                               |
|                        |                                                                    | 17 yrs and over                                                                                                              |                                                                                                             |                               |
|                        |                                                                    | Grandparents                                                                                                                 |                                                                                                             |                               |
|                        |                                                                    | Rettnetters                                                                                                                  |                                                                                                             |                               |
|                        |                                                                    | Professionals                                                                                                                |                                                                                                             |                               |
| <b>Saturday May 23</b> | 6:30a-10:30a                                                       | Breakfast                                                                                                                    | At your leisure                                                                                             | Riverside Hearth Restaurant   |
|                        | 7:45a-8:30a                                                        | Rett Syndrome 101                                                                                                            | Alan Percy, MD, Director UAB Rett Center at the University of Alabama Civitan International Research Center | General Session Ballroom A    |
|                        | 9am                                                                | Keynote Address "Fighter Mom: For Mothers and Others"                                                                        | Martha Slay, FightSMA                                                                                       | General Session Ballroom A    |
|                        | 9:30am                                                             | Catching a Glimpse and Fueling the Flames of the Hidden Torch Within                                                         | Linda Burkhart, Simplified Technology                                                                       | General Session Ballroom A    |

25<sup>th</sup> Annual Conference Program - IRSF  
"Celebrating the Torch Within"

May 22-25, 2009  
Lansdowne Resort and Spa in Leesburg, Virginia

[www.rettsyndrome.org](http://www.rettsyndrome.org)

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|  |               |                                                                                                        |                                                                    |                             |
|--|---------------|--------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------|-----------------------------|
|  | 10:30am       | Break                                                                                                  |                                                                    |                             |
|  | 10:45am       | Let's Get Together and Communicate!                                                                    | Susan Norwell, M.S. Ed.                                            | General Session Ballroom A  |
|  | 11:30am       | "Jumpstarting" Literacy Learning: It's never too late to start!                                        | Judy Lariviere, M.Ed., OTR/L                                       | General Session Ballroom A  |
|  | 11am–2pm      | Lunch                                                                                                  | At your leisure                                                    | Riverside Hearth Restaurant |
|  | 1:30p-2:30p   | Communication: In High School and Adulthood                                                            | Susan Norwell, M.S. Ed.                                            | Concurrent A                |
|  |               | Successful Use of "Eye-Gaze" Technology: From Assessment to Conversation                               | Judy Lariviere, M.Ed., OTR/L                                       | Concurrent A                |
|  |               | Measurable IEP Goals                                                                                   | Irene Moore, <i>PEATC</i>                                          | Concurrent A                |
|  |               | Integration in the Elementary School Environment – A Success Story                                     | Jennifer Ethridge and Mickie McCool                                | Concurrent A                |
|  |               |                                                                                                        |                                                                    |                             |
|  | 1:30pm – 4pm  | Partner-Assisted Scanning with PDD Communication Books: Strategies for Children who have Rett Syndrome | Linda Burkhart, <i>Simplified Technology</i>                       | Workshop Ampitheater        |
|  |               |                                                                                                        |                                                                    |                             |
|  | 2:40pm-3:40pm | Measurable IEP Goals                                                                                   | Irene Moore, <i>PEATC</i>                                          | Concurrent B                |
|  |               | Creating Her Future Care Plan                                                                          | Mary Anne Ehlert, <i>Protected Tomorrows</i>                       | Concurrent B                |
|  |               | Integration in the Elementary School Environment – A Success Story                                     | Jennifer Ethridge, <i>Educator</i><br>Mickie McCool, <i>Parent</i> | Concurrent B                |
|  |               | Carrying the Fundraising Torch: A "How-To" Workshop                                                    | Jennifer Endres, <i>IRSF</i>                                       | Concurrent B                |
|  |               | Lighting Your Path to the Transition to Adulthood and Community Programs                               | Tia Marsili, <i>The ARC of Northern Virginia</i>                   | Concurrent B                |
|  |               |                                                                                                        |                                                                    |                             |
|  | 3:40pm        | Break                                                                                                  |                                                                    |                             |
|  |               |                                                                                                        |                                                                    |                             |
|  | 4pm-5pm       | How to Talk to Schools So Schools Will Listen (and Listen So Schools Will Talk)                        | Irene Moore, <i>PEATC</i>                                          | Concurrent C                |
|  |               | Communication: In High School and Adulthood                                                            | Susan Norwell, MS Ed                                               | Concurrent C                |
|  |               | Successful Use of "Eye-Gaze" Technology: From Assessment to Conversation                               | Judy Lariviere, M.Ed., OTR/L                                       | Concurrent C                |
|  |               | Creating Her Future Care Plan                                                                          | Mary Anne Ehlert, <i>Protected Tomorrows</i>                       | Concurrent C                |
|  |               | Lighting Your Path to the Transition to Adulthood and Community Programs                               | Tia Marsili, <i>The ARC of Northern Virginia</i>                   | Concurrent B                |
|  |               |                                                                                                        |                                                                    |                             |
|  | 5:10pm        | Dads Panel                                                                                             | Panelists                                                          | General Session Ballroom A  |

|                      |                |                                                                     |                                                                                                                                    |                             |
|----------------------|----------------|---------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------|-----------------------------|
|                      | 5:45pm         | Siblings Panel                                                      | Panelists                                                                                                                          | General Session Ballroom A  |
|                      |                |                                                                     |                                                                                                                                    |                             |
|                      | 6p-10p         | Dinner                                                              | At your leisure                                                                                                                    | Riverside Hearth Restaurant |
|                      |                |                                                                     |                                                                                                                                    |                             |
|                      | 7:30p          | Tribute Reception and Auction                                       |                                                                                                                                    | Ballroom A                  |
|                      |                |                                                                     |                                                                                                                                    |                             |
|                      |                |                                                                     |                                                                                                                                    |                             |
| <b>Sunday May 24</b> | 6:30am-10:30am | Breakfast                                                           | At your leisure                                                                                                                    | Riverside Hearth Restaurant |
|                      | 7:45am-8:15am  | Rett Genetics 101                                                   | Carolyn Schanen, MD, PhD Nemours                                                                                                   | General Session Ballroom A  |
|                      | 8:30am         | Understanding the Signs and Symptoms of Rett Syndrome in Your Child | SakkuBai Naidu, MD, <i>Rett Syndrome Research Project and Dept of Neurology at the Kennedy Krieger Institute (KKI)</i>             | General Session Ballroom A  |
|                      | 9:15am         | Epilepsy and Seizure Management                                     | tbd                                                                                                                                | General Session Ballroom A  |
|                      | 9:35am         | Growing Straight and Tall with Rett: Bone and Muscle Issues         | Paul Sponseller, MD, Orthopedist, <i>Kennedy Krieger Institute</i>                                                                 | General Session Ballroom A  |
|                      | 10am           | Break                                                               |                                                                                                                                    |                             |
|                      |                |                                                                     |                                                                                                                                    |                             |
|                      | 10:15am        | Gastroenterology                                                    | Anil Darbari, MD, <i>Director, Gastroenterology and Nutrition Program and Feeding Disorders Program, Kennedy Krieger Institute</i> | General Session Ballroom A  |
|                      | 10:35am        | Endocrinology: Bone Issues and their Treatment in Rett Syndrome     | Jay Shapiro, MD, <i>Director, Bone Program, Kennedy-Krieger Institute</i>                                                          | General Session Ballroom A  |
|                      | 10:50am        | Neuropsychology                                                     | Cynthia Salorio, MD, <i>KKI</i>                                                                                                    | General Session Ballroom A  |
|                      | 11:05am        | Behaviors in Rett syndrome                                          | Dr Naidu for Elaine Tierney, MD                                                                                                    | General Session Ballroom A  |
|                      | 11:20am        | Well Child and Adult Care Overview                                  | Jane Lane, RN, <i>UAB and IRSF</i>                                                                                                 | General Session Ballroom A  |
|                      | 11:40a-12:30pm | Physician Q&As                                                      | All – Breakout Meeting Rooms                                                                                                       | General Session Ballroom A  |
|                      |                |                                                                     |                                                                                                                                    |                             |
|                      | 11am-2pm       | Lunch                                                               | At your leisure                                                                                                                    | Riverside Hearth Restaurant |
|                      |                |                                                                     |                                                                                                                                    |                             |
|                      | 1:30p          | Physical Therapy                                                    | Jennifer Swain, Physical Therapist, <i>Kennedy Krieger Institute</i>                                                               | Concurrent A                |
|                      |                | To Sleep, Perchance to Dream: Sleep Disorders in Rett Syndrome      | Judy Barrish, RN, <i>Blue Bird Rett Center Baylor College of Medicine</i>                                                          | Concurrent A                |
|                      |                | The Maturing Woman with Rett Syndrome: From Puberty to Menopause    | Jane Lane, BSN, RN, <i>UAB and IRSF</i>                                                                                            | Concurrent A                |
|                      |                | Music Therapy                                                       | Sara Jourdan, <i>Simple Changes</i>                                                                                                | Concurrent A                |

|                      |       |                                                                          |                                                                                                                                                         |                               |
|----------------------|-------|--------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------|
|                      | 2:30p | Physical Therapy                                                         | Jennifer Swain, Physical Therapist, <i>Kennedy Krieger Institute</i>                                                                                    | Concurrent B                  |
|                      |       | To Sleep, Perchance to Dream: Sleep Disorders in Rett Syndrome           | Judy Barrish, RN, <i>Blue Bird Rett Center Baylor College of Medicine</i>                                                                               | Concurrent B                  |
|                      |       | The Maturing Woman with Rett Syndrome: From Puberty to Menopause         | Jane Lane, BSN, RN, <i>UAB and IRSF</i>                                                                                                                 | Concurrent B                  |
|                      |       | Music Therapy                                                            | Sara Jourdan, <i>Simple Changes</i>                                                                                                                     | Concurrent B                  |
|                      | 3:30p | Break                                                                    |                                                                                                                                                         |                               |
|                      | 3:45p | <i>Science and Research Presentations and Discussion</i>                 |                                                                                                                                                         | General Session Ballroom A    |
|                      |       | World Congress Update on Therapies: Those Mice are Working Hard for you! | Carolyn Schanen, MD, PhD <i>Nemours</i>                                                                                                                 | General Session Ballroom A    |
|                      |       | What is Stem Cell Research?                                              | Antony Horton, PhD, <i>IRSF Chief Science Officer</i>                                                                                                   | General Session Ballroom A    |
|                      |       | NIH RDCRN Natural History Study                                          | Alan Percy, MD, <i>Director UAB Rett Center at the University of Alabama Civitan International Research Center</i>                                      | General Session Ballroom A    |
|                      |       | Rett Syndrome Classification and DSM-V                                   | Walter Kaufmann, MD, <i>Director of the Center for Genetic Disorders of Cognition and Behavior at Kennedy Krieger Institute and Chair of RettSearch</i> | General Session Ballroom A    |
|                      | 4:15p | Research Panel Q&A                                                       | All                                                                                                                                                     | General Session Ballroom A    |
|                      | 4:45p | Closing Remarks                                                          | Paige Nues, <i>IRSF</i>                                                                                                                                 | General Session Ballroom A    |
|                      | 5:15p | Carrying the Fundraising Torch: A "How-To" Workshop                      | Jennifer Endres, <i>IRSF</i>                                                                                                                            | Breakout Room                 |
|                      | 7:30p | "Silent Angels" Movie Night                                              | All are welcome                                                                                                                                         | Amphitheater                  |
|                      |       |                                                                          |                                                                                                                                                         |                               |
| <b>Monday May 25</b> | 9am   | Crackerbarrels: Learnings and Takeaways                                  |                                                                                                                                                         | Ballroom D                    |
|                      |       | 7 yrs and under                                                          |                                                                                                                                                         |                               |
|                      |       | 8 – 16 yrs                                                               |                                                                                                                                                         |                               |
|                      |       | 17 yrs and over                                                          |                                                                                                                                                         |                               |
|                      | Noon  | Registration/Help Desk Bookstore and close                               |                                                                                                                                                         | Ballroom Foyer and Ballroom C |